

The Shame Behind Being Chronically Ill



There have been many times since my diagnosis of relapsing-remitting MS in 2015 that I have felt shame for being different. I feel shame when someone calls out my gimp or when I have to admit to a coworker that I can't assist them with something if I'm flaring.

I have been shamed by others; those who do not understand what it's like to be chronically ill, and who extend minimal compassion or understanding.

Something I experienced recently, however, was being shamed by others experiencing chronic illnesses - even others with MS. I never thought I would experience a situation like this, it never even entered my personal radar - but it's very real, and it happens.

I feel fortunate in my lifestyle where I can choose to exercise at my local gym or stay home and have a "bed day" when I'm feeling crummy. Lately, because of my social media presence and my choice to share my MS journey, I open the door for shame and ridicule.

When I choose to go to the gym, whether it be a good or bad day, my inbox is aflame with messages like:

- "Just rub it in that you can go to the gym, why don't you."
- "You shouldn't exercise and exacerbate symptoms."
- "No one cares that you work out - try sharing something relatable to those of us who can barely move."

When I decide to share a recipe I recently made because sharing is caring, whether it's healthy or hearty, I often receive messages along the lines of:

- “You’re making it impossible to live up to the expectation to eat this well all of the time.”
- “You shouldn’t be sharing recipes outside of the Wahl’s protocol – it’s dangerous for others with MS.”
- “You’re eating THAT? Why would you eat THAT when you should be eating THIS?”

I expected to feel a little like an outsider to the rest of the world once I fully accepted that I’m different; I never expected to feel like an outsider within my own community of MS warriors.

Through the decision to share my personal struggle with others on the internet, I’ve learned one very important lesson.

You are never going to be able to appease everyone, and that’s okay.

I have not once replied to these types of messages with anger or humiliation because I am authentically sharing the aspects of my life I want others to see. The good days, the ugly days, the delicious days, the healthy days, the bed days. These are all days within my own personal journey, and that is my own personal forum to share it.

So, the next time you feel like sharing an aspect of your journey with the rest of the world, prepare yourself. Prepare yourself for feedback you didn’t ask for. Prepare yourself for unwarranted advice. But most of all, prepare yourself for unconditional love and support from strangers around the world who genuinely love to see you thrive.

I love to share my journey because of the impact it has on others who need reassurance, a kind word, or a friend. The ratio of positive far outweighs the negative and the community we’ve built exists because of the brave people out there who are fighting every day.

We are our own strength, so why not be stronger together?